THE STUDY OF ROLE DIVISION AND STRESS IN FAMILIES WITH HANDICAPPED CHILDREN

A Thesis

by

CAROL MARIE TRIVETTE

Submitted to the Graduate School

Appalachian State University

in partial fulfillment of the requirements for the degree of

MASTER OF ARTS

May 1982

Major Department: Special Education

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APPROVED BY:

Chairperson, Thesis Committee

Member, Thesis Committee

Member, Thesis Committee

Member, Thesis Committee

Chairperson, Department of Special Education

Dean of the Graduate School

ABSTRACT

A STUDY OF ROLE DIVISION AND STRESS IN FAMILIES WITH HANDICAPPED CHILDREN. (May 1982)

Carol Marie Trivette, B. A., University of North Carolina at Chapel Hill

M. A., Appalachian State University

Thesis Chairperson: Dr. Arthur Cross

Adopting an ecological perspective, the purpose of this study was to examine how role management related to levels of stress in families with preschool handicapped children. The independent variable, role management, was divided into three parts for investigation: role accumulation role congruence, and satisfaction with the performance of roles. The dependent measures of stress were time demands, social support, family integration, and family opportunities.

Participants in this study were 54 families who were or had been involved in an early intervention program. They completed two self-report instruments: the Parent Role Scale and the Questionnaire on Resources and Stress. A number of significant relationships were found. The number of roles performed, role accumulation, was significantly related to the measure of family integration. Role congruence, the difference between who performs the role now and who they want to perform the role, was

significantly related to family integration and family opportunities. Statistical analyses revealed that satisfaction with the performance of roles was significantly related to all four measures of stress. High satisfaction with role performance was related to less time demands, more social support, more family integration, and more family opportunities.

ACKNOWLEDGEMENTS

This Thesis is the culmination of many graduate school experiences. There are several people I wish to thank:

Dr. Max Thompson, who provided me with many new opportunities from which to learn and the support to try them;

Dr. Art Cross, who sanctioned my love for families and always gave me a new goal to meet;

Dr. Carl Dunst, who showed me that research and service models can work together and gave me the chance to conduct this research;

Dr. Linda Blanton, for her editorial assistance.

Dedication

To Dewitt, Mary Ellen, Paul, Janese, and Robert - because of you I know the love and support which comes from an amazing family;

To Tony N., Mark, David, Tony D., Charles, Temika, Randall, Traci, Michael, Tigger and their families -
it is for you this research was conducted.

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Chapter I

INTRODUCTION

Traditionally, a considerable amount of effort has been expended on the study of the characteristics of the individual handicapped child in conducting research or providing educational or psychological services. Such an approach has generally viewed the child as an isolated unit, and interventions have been designed which direct their strategies to the child only. Although this approach is still widely used, especially in the field of education, over the last few years there has been a growing recognition in the value of an ecological view of handicapped children (Bronfenbrenner, Avgan, & Henderson, 1977; Cross, 1980; Bristol, 1979).

An ecological model (e.g., Bronfenbrenner, 1977) suggests that the researcher and practitioner look beyond the child to the family unit and to the numerous people, places, and events which impact on each person in the family. To help handicapped children remain with their families, factors which help or hinder this goal must be examined. This approach attempts to explain the relationship between support and stress within a broader perspective rather than simply examining the effect of the child on the family. As noted by Bronfenbrenner (1977), ecological research "focuses on the progressive accommodation, throughout the life span, between the growing human organism and the changing environments in which it

actually lives and grows" (p. 513).

Once the researcher adopts an ecological perspective, the relationship between different forces and factors become prime considerations in conducting research studies (e.g., the study of factors which affect families with handicapped children). It becomes important to identify how support and stress are related to one another, inasmuch as they will affect the family's ability to keep the child at home. Independent variables may include characteristics of all family members, types or patterns of family interaction, role management, and relationships with extended family members and neighbors. These relationships must be viewed as always changing and affecting each other. This makes it difficult to identify one explanatory variable and say it will remain consistent. Though it is perhaps more difficult to study families from this perspective, it may be a more productive way to obtain an accurate characterization of family functioning.

It was beyond the scope of this study to examine in detail all the relationships between members of different ecological units. This study specifically examined the relationship between role management within families of preschool handicapped children and the degree of stress reported by the parents. The independent variable was role management and the dependent variable was levels of stress. As ecological research, it was important to examine an independent variable beyond those commonly identified (e.g., type of disability the child has or socio-economic factors). By definition an independent variable is manipulated to create change in the dependent variable. This study used an independent variable, role

management, which could be manipulated by the practitioner or family, as well as the researcher, to create change in the dependent variable, levels of stress.

There were three research questions to be answered:

1. What is the relationship between reported role accumulation and levels of stress? Role accumulation is defined as "the number of roles performed by either spouse" (Cross, 1980, p. 39).

2. What is the relationship between reported role congruence and levels of stress?

3. What is the relationship between reported satisfaction with role performance and levels of stress? Satisfaction with role performance refers to the "perception of competence of the various performances" (Cross, 1980, p. 39).

This study of families with young handicapped children identified aspects of role management and their relationship with reported stress. Specifically, the degree of role congruence among parents was explored as it related to the amount of stress experienced. How the amount of role accumulation related with stress was another aspect of this study. The third element of role division, satisfaction with the performance of a role, was tested in relation to reported stress.

Chapter II

SUMMARY OF SELECTED LITERATURE

For the purpose of establishing a perspective, the review of the literature examined the characteristics of families with non-handicapped children and the impact of children on these families. Following this, the paper examined various characteristics of families with handicapped children. The general effects of these children and stress of various handicaps on the families will be explored. Stress and the factors which affect stress will be presented as they related to marital satisfaction. The third section reviewed the literature on the theory of role management in families of handicapped children and how role management affects marital satisfaction and stress.

Families of Nonhandicapped Children

Characteristics of normal families. Very little research has been conducted which describes the working of normal or healthy families. What data are available, however, suggest that there are a variety of variables which create the healthy family (Lewis, Beavers, Gossett, & Phillips, 1976). Lewis et al. attempted to identify what factors might contribute to the make-up of "healthy" families. A sample of 12 healthy families was divided into two groups which were labeled (1) optimal and (2) adequate. Data were collected on these families from six hours of videotaped interviews conducted by two family therapists. The findings of Lewis et al.

are interesting because they shed some light on the workings of healthy families. There were some differences in role satisfaction among wives (nearly all were housewives). In the optimal families, the wives reported a great degree of marital and family satisfaction. The wives from adequate families often expressed disappointment and frustration in their roles and frequently had psychophysiologic symptoms (e.g., headaches, fatigue).

Lewis et al. (1976) also found a number of interesting aspects as to how these healthy families functioned as a unit. However, the most interesting finding was that there was no single trait identified for the optimal families which the adequate families did not have. These optimal families seemed to have characteristics which were interrelated. It was the combination of many factors working in a variety of ways which created the optimal families.

One variable which played a part in this explanation for the optimal functioning of a family was "parent coalitions" (Lewis et al., 1976). When the marriage was able to meet the needs of both parents, a firm coalition was formed between the parents. This led the marriage and family towards family closeness, equalitarian interaction, and the ability to negotiate conflicts. Other variables which Lewis et al. identified were positive attitudes toward human interactions, approval of subjective views, high levels of personal autonomy, and the ability to perceive themselves as others see them.

Effects of childbirth on families. As pointed out by Lewis et al. (1976) marital coalition or marital satisfaction was related with optimal family functioning. The birth of a couple's first

child is an event which is often excitedly anticipated. However, it has been shown in a number of studies (Christensen, 1968; Dyer, 1963; Hobbs, 1965; Luckey & Bain, 1970; Rossi, 1968) that the birth of the first child has an impact on the marital relationship. Rollins and Feldman (1970) reported in their review of 12 studies that there was a decrease in marital satisfaction for the newly married couple from the birth of the first child to the oldest child entering school. This seemed especially true for females. Supporting the idea that the parental experience created a certain degree of stress, Burke and Abidin (1980) pointed out that usually parents are able to adjust to the changes.

Rollins and Galligan (1978) theorized that the impact of children on the marriage followed a U-shaped pattern. When first married, there would be a high degree of satisfaction. A decrease in satisfaction occurred about the time of the birth of the first child. When children began to leave the home, there was an increase in satisfaction. There are studies which support this claim among middle class populations (Rollins & Feldman, 1970; Rollins & Cannon, 1974). However, various methological questions made these findings at least questionable. Spanier, Lerner, and Aquilino (1978) discussed the problems with these studies because most were based on cross-sectional samples. They noted concerns about the drop out effect of divorced couples and the need for couples to justify why they remained in a marriage for a long time.

Although there may be controversy concerning the effects of a child on the family's life cycle, there are studies (Wente &

Crockenberg, 1976; Pedersen, Anderson, & Cain, 1980) which demonstrated the effects of the marital relationship during the early stages of child development. Nye (1976) discussed the need for the couple to redefine and adjust to new roles once a child is born. A study by Wente and Crockenberg (1976) examined this adjustment period for fathers. These 46 fathers responded to a questionnaire and were involved in a semi-structured interview. The researchers reported that the wife-husband relationship correlated (.60) highly and significantly ($p < .001$) with the husbands' total adjustment score. The more the husband perceived a negative impact on his relationship with his wife, the more difficulty he reported in this overall adjustment.

In a study involving 41 five-month-olds, Pedersen, Anderson, and Cain (1980) described the relationship between mother competency at child feeding and the quality of the husband-wife relations. Mothers were assessed in feeding their five-month-olds, and interviews were conducted to determine the quality of the relationship. They observed that when the father was more supportive of the mother, she was more effective in feeding. High conflict and tension was associated with more inept feeding by the mother.

Families of Handicapped Children

In discussing the family which has a handicapped child, there are a variety of factors which need to be reviewed. There will be several effects on the family and these effects will vary depending on the type of handicapping condition. Especially important as seen

in the above review will be to investigate how the added stress relates to the marriage and various factors effecting marital satisfaction.

Effects of the child. Burke and Abidin (1980) noted that there was stress in raising children which arose from the many facets of the parent/child system. Most families they found adapted to these stress factors. They cautioned that "the existence of stress in extreme amounts may result in adverse consequences if necessary interventions are not undertaken" (Burke & Abidin, 1980, p. 517-518).

The birth of a handicapped child into the family adds a greater proportion of stress to the family than the simple addition of a new child (Tavormina & Kralj, 1975; Cummings, 1976; Cummings, Bayley, & Rie, 1966). Cummings et al. (1966) identified the effects of this stress on mothers of mentally retarded, chronically ill, and neurotic children as compared to mothers with normal children. Among the mothers with handicapped children, Cummings et al. (1966) found a higher occurrence of depressed feelings, more preoccupation with the child, more difficulty in handling anger at the child, greater feelings of possessiveness toward the child and a decreased sense of maternal competence, than among mothers of normal children. Fathers of mentally retarded and chronically ill children had more depression, preoccupation with the handicapped child, decreased satisfaction with his wife, decreased self-esteem, and a need for more order and routine than did fathers of healthy children (Cummings, 1976).

Korn, Chess, and Fernandez (1978) interviewed 243 parents with a child who had handicaps due to congenital rubella. Of this group only 3.7% reported parental discord due to the birth of the handicapped child. Almost a quarter (22.2%) of the parents experienced a significant degree of disruption as related to the type and number of handicaps, mental retardation, behavior disorder, and child temperament at a significant level ($p<.05$).

Stress of various handicaps. Measures of stress levels between various types of handicapping conditions are important to consider. As noted above (Korn et al., 1978), the types of handicaps and the number of handicaps are associated with the degree of reported stress. In three studies (Holroyd & McArthur, 1976, Holroyd, Brown, Wikler, & Simmons, 1975; Holroyd & Guthrie, 1979), the Questionnaire of Resources and Stress (QRS) compared stress levels among families with children who had different handicapping conditions. The first study involved children with neuromuscular diseases, the second autistic children and the third Down's syndrome and autistic children.

Holroyd and McArthur (1976) examined the relationship of mental retardation and stress between Down's syndrome, autistic, and outpatient psychiatric clinic children. They had a total of 76 families participating in the study which found through the QRS that the scales which measured retardation/social dependency separated the mothers of autistic and Down's syndrome children from the mothers of the clinic population. Holroyd and McArthur (1976) also reported a variation in the amount and types of stress experienced

between the mothers of autistic and Down's syndrome children. Mothers of autistic children were (a) more upset and disappointed about the child, (b) more concerned about the child's dependency, and (c) more concerned about the effect of their child on the rest of the family and family integration. These mothers had more problems with physical disability and were more aware of personality and behavioral problems.

An attempt was made to measure the stress differences in families of institutionalized and noninstitutionalized autistic children (Holroyd, Brown, Wikler, & Simmond, 1975). In this study the QRS was used in conjunction with an interview to evaluate the level of stress. The investigator found no difference between the stress levels as measured by the two instruments. Within the QRS scales, the severity of the child's impairment and the mother's pessimism distinguished between the two groups.

Another study by Holroyd and Guthrie (1979) explored the differences in stress with parents of children with neuromuscular diseases and parents of children with a psychiatric diagnosis. The measure of stress revealed differences in pessimism, problems in family integration, and problems in the child's personality. Parents of neuromuscular children were more pessimistic. The parents of psychiatric children reported more problems in family integration and in the child's personality.

Stress on the marital relationship. A number of studies (Friedrich, 1979; Bradshaw & Lawton, 1978; Howard, 1978) have demonstrated the relationship between stress and marital satisfaction.

Friedrich (1979) had 98 mothers of moderately retarded and cerebral palsy children complete several scales including the QRS and the Locke-Wallace Marital Adjusment Inventory. Using stepwise multiple regression analysis, he found the most significant ($p<.01$) predictors of coping behaviors were (a) marital satisfaction, (b) child's residence, and (c) child's sex. Marital satisfaction alone was responsible for 79% of the variance in the independent variable by the dependent variable. Friedrich (1979) summed up by stating "the most significant of the contributing variables was the mother's feeling secure in the marital relationship" (p. 1141).

A British study (Bradshaw & Lawton, 1978) which was conducted with 303 mothers of severely disabled children found similar results. Levels of stress varied according to the mother's satisfaction with the marital roles.

Tew, Payne, and Laurence (1974) discovered a deterioration of the marital relationship over the years in families of spina bifida children. Of the 59 couples interviewed only one in four appeared free from marital difficulties.

Factors effecting marital satisfaction. The work of Farber (1959) studied 240 families with a mentally retarded child. These families had the following characteristics: Caucasion; one or both parents regarded the child as severely mentally deficient; the child was 16 years or under; the child was born in the present marriage; and the parents were married and living together during the study. The procedure was a combination of self-reported questionnaires and two hours of interviews. Farber (1959) identified

numerous independent variables including sex and age of the child, social status, religious preference, and relationships with extended families and neighbors. The dependent variables were an index of sibling role tension and an index of marital integration. Marital integration was the degree of agreement on domestic values by husband and wife and the estimation of existing marital role tension.

There were a variety of findings which related to marital integration. For parents of mentally retarded boys who lived at home, the marital integration for these parents was lower than for parents of mentally retarded girls. The presence of a retarded boy in lower class families had a more acute effect on the parent's marriage than the presence of a retarded girl. As mentally retarded boys grew older, they had an increasingly disruptive effect on the marriage. Marriage integration of parents with an institutionalized child was higher than parents with a retarded boy at home.

In the area of community participation, Farber (1959) also obtained interesting results. It appears that outside involvement can be either supportive or nonsupportive of marital integration. In this study (Farber, 1959), it was observed that the marriages of non-Catholics were more adversely effected with the retarded son at home than in the institution. Where the son lived made little difference in the marital integration of the Catholics. He showed that men active in formal organizations which did not pertain to relition or mental retardation tended to have relatively low marital integration.

In terms of support, Farber (1959) reported that frequent interaction with the wife's mother was related to high marital integration. However, seeing the husband's mother frequently was related with low marital integration. In summary, Farber's (1959) research showed that there are a variety of influences on marital integration in the family of a handicapped child.

Roles Within Families

The idea of roles within the family of a handicapped child is important to the understanding of how the family works (Tavormina & Kralj, 1975). From the understanding of how roles are managed, it is then possible to examine how role performance related to stress and marital satisfaction (Schaefer & Edgerton, 1981; Lee, 1979; Cross, 1980).

Theory or role management and marital satisfaction. Tavormina and Kralj (1975) concurred that a handicapped child disrupted the family's equilibrium and placed the family under stress until they could adjust and redistribute roles and responsibilities. The authors proposed that the "quality of the couple's interaction can predict subsequent family adjustment with a handicapped child" (Tavormina & Kralj, 1975, p. 4). Four patterns for establishing balance in a relationship were discussed, though they did not feel these were the only possible patterns. The first possibility was emotional divorce. Here the mother put all of her energy into the child and the father put his into his job. Therefore the couple drew away from each other into emotional divorce. The second pattern was a child-centered family. In this system, the families

stayed together, but the parents refocused energy from their relationship to the child. The child became the point of reference for the family.

A coupled-centered family was the third pattern considered by Tavormina and Kralj (1975). In this pattern, the bonds between the parents grew stronger but at a loss to the child. The parents came together, but had strong feelings of rejection for the child. The last pattern was that of the supportive family. In this case, the mother reduced energy outside the home and redirected it to the child. The father also reduced energy and invested it in the family and in supporting his wife. The extra energy needed for the handicapped child was not taken from the parental relationship but from other sources. The description of how parents of handicapped children dealt with the added stress reflected the importance of marital relationships and the effects of roles played.

Roles as they effect marital satisfaction and stress. The management of roles and satisfaction of this management within a family were two aspects which determined the satisfaction of the marital relationship (Nye, 1976; Schaefer & Edgerton, 1980). The concept of a family group where a person had many needs met within this family unit at the loss of some personal autonomy is a structure which many people in this society are willing to develop (Nye, 1976). The division of roles and the completion of them could lead either to satisfaction or conflict within this relationship according to Nye (1976). He claimed that when one spouse was accomplishing things which created losses for the other spouse, then

conflict could be expected. By contrast, if the gains of one spouse did not lessen the gains of the partner, then the regards would be high, and both would be satisfied.

Lewis and Spanier (1979) described the complementary agreement of roles perceived by partners as a "role fit" (P. 284). The more complementary the fit, then the more partners reported high marital quality. However, not only must the division of roles complement one another, there must be agreement reached concerning how the division of roles will operate. Nye (1976) suggested that common values were important in a satisfactory division of roles. If a couple both agreed with the traditional division of roles, husband as breadwinner and wife as homemaker, then the satisfaction with roles would be high and stress would be low. A wide discrepancy in the way the roles would be divided was going to cause conflict.

Joint conjugal role organization was found by Lee (1979) as positively related to marital satisfaction. As explained by the author, this joint conjugal role design is characterized by high interchangeability of household and other tasks and companionship in leisure activities. Similarly, Nye (1979) emphasized the importance of role division being based on individual skills and preferences.

The perceived competence at which a person performs a role is another factor in the amount of stress experienced (Nye, 1979). This level of perceived competence was the assessment of both parents.

The concept of "role strain" was defined by Spanier, Lerner, and Aquilino (1978, p. 337) as the amount of difficulty a person experienced when she/he perceived that she/he could not measure up to the expectations of a role. Fathers often felt that they were not prepared to successfully accomplish the role of fatherhood (Wente & Crockenberg, 1976). Spanier et al. (1978) asserted that the role strain for parents of a handicapped child was very likely and would lead to stress in the overall family life. The perceived deficit areas may be either emotional resources or physical resources.

Rollins and Galligan discussed the "perceived quality of role enactment" (1978, p. 81) by both partners as antecedents to marital satisfaction. This was supported by Nye (1979) when he maintained that competence in roles was a useful predictor of marital satisfaction. He proposed that partners stayed in relationships when their needs were being met and competency in fulfilling roles added to the sense of satisfaction.

Among families with handicapped children, there appears to be some differences with the satisfaction of various roles. Cross (1980) explored the satisfaction of roles with a total of 50 families. Of these families, 25 were described as adequate in coping with the stress of a handicapped child and the rest were described as successful. As a measure of role division and satisfaction, the author used the Parent Role Scale (PRS) which will be discussed later. This study demonstrated that the mothers in successful families were significantly ($p<.02$) more satisfied with the

role of Confidant/Supporter. Fathers in successful families were more satisfied with the role of Discipline ($p<.005$).

Though there were only a few differences established among these families, it is possible that since the families had all been chosen because they were average or above in their coping skills, that there was simply not enough distinction to show a difference in roles and coping strategies. A population which has not been preselected for good coping skills might show a broader range of variance.

Schaefer and Edgerton (1981) used the PRS and the Locke-Wallace Marital Adjustment Scale with 46 intact families of which 33 had a handicapped child. The clearest finding reported in this study was that mother's marital happiness and life satisfaction were found to be consistently correlated (.52) with high father involvement in the family roles.

Conclusions

Based on this literature review, several conclusions can be made. First, in healthy families, marital satisfaction is an important aspect, and the birth of the first child will have an impact on this relationship. Second, families with handicapped children must handle a great deal of stress, and this stress will vary according to the severity of the handicap. Third, an important indicator of how well the stress will be handled is the quality of the marital relationship. Fourth, a variety of factors contribute to marital satisfaction. Fifth, aspects of role management will affect the degree of marital satisfaction and stress within the family.

Chapter III

METHODOLOGY

This study was designed to investigate the relationship between role management and stress in families with young handicapped children. The procedures, research design, and a description of the analysis of the data are described in this chapter.

Subjects

The subjects consisted of 54 parents of preschool handicapped children. These families were selected from among all clients of the Family, Infant and Preschool Program (FIPP), an early intervention program serving children between birth and six years of age who are mentally retarded, sensory handicapped, physically handicapped or at-risk for future developmental problems. FIPP serves a 20 county catchment area in western North Carolina and has about 250 families participating in various activities offered through their program during a single year.

Two criteria were used in selecting subjects to participate in this study:

1. Families must have been active participants in the program for more than four months or inactive for no longer than six months at the beginning of the study.
2. Families must have included (a) both natural parents; (b) parents who have legal custody; (c) foster parents; or (d) a

relationship similar to a husband/wife marriage in which one of the partners was the natural parent.

Instruments

The two instruments utilized in this study were the Parent Role Scale (Gallagher & Cross, 1979) and the Questionnaire on Resources and Support (Holroyd, 1973). Both instruments are self-report measures.

The Parent Role Scale (PRS). The independent variable, role management and role satisfaction, was measured by the Parent Role Scale. The PRS consists of a list of 20 roles which must be performed in all families with young children. The roles in the PRS include the following: Provider; Resource Divider; Bookkeeper-Accountant; Protector-Defender; Food Shopper; Food Preparer and Server; Home Maintenance-Equipment; Home Maintenance-Outside; Home Maintenance-Internal; Moral Leader; Social Host; Communicator (Business); Communicator (Social); Confidant Supporter; Teacher; Child Discipline; Nurse; Transporter; Clothing Selector; and Recreation Leader.

Cross (1980) described how the scale is administered and how the data can be used:

> The respondent is asked to describe his/her view of: (a) who currently performs the role; (b) how would you prefer the role be performed; and (c) degree of satisfaction with the role performance. Questions (a) and (b) are responded with the options of (1) husband only (2) husband with assistance from wife (3) mutual shared performance (4) wife with assistance from husband (5) wife only. Question (c) is answered with options of low

> to high satisfaction. The total score of section (a) yields an index of role accumulation; which refers to the number of roles performed by either spouse. The absolute difference between the score on part (a) and the score on part (b) for each role, when summed for all roles, yields an index of role congruence. The total score of section (c) yields an index of role satisfaction, which refers to the perception of competence of the various performances. (p. 39)

The PRS is a newly developed instrument. It has been used in several studies (Cross, 1980; Schaefer & Edgerton, 1981) and in both investigations, adequate reliability was reported.

The Questionnaire on Resources and Stress (QRS). The dependent variable, stress, was measured by the Questionnaire on Resources and Stress (Holroyd, 1973). The QRS, developed by Jean Holroyd and her associates, is a 285 true-false item questionnaire which has a readability level estimated at Grade 6. It was designed to measure 15 different factors relevant to families caring for handicapped or chronically ill family members. The instrument includes the following scales: Poor Health/Mood; Excess Time Demands; Negative Attitude Toward Index Case; Overprotection/Dependency; Lack of Social Support; Overcommitment (Martyrdom); Pessimism; Lack of Family Integration; Limits on Family Opportunity; Financial Problems, Physical Incapacitation; Lack of Activities for Index Case; Occupational Limitation for Index Case; Social Obtrusiveness; and Difficult Personality Characteristics.

The different scales on the QRS fall into three broad categories: (1) personal problems of the respondents as related to the child; (2) family problems as related to the child; and (3) limitations or problems of the handicapped child. As described in the review of literature, the QRS has been used in a variety of studies (Holroyd & Guthrie, 1979; Holroyd & McArthur, 1976; Holroyd et al., 1975) which examined stress as it related to different handicapping conditions.

In the current study, the QRS was not used to compare children's diagnoses. Identifying handicapping conditions as a cause of stress does not provide the practitioner or family with information which can be used to reduce the levels of stress. The current study of ecological factors used the QRS to examine stress as it related to role management.

This study examined four QRS scales in relationship to the Parent Role Scale. These were Excess Time Demands, Lack of Social Support, Lack of Family Integration, and Limits on Family Opportunity. Selected examples of each scale used in this study are presented in Table 1. These scales were chosen because they related to the concepts of role management and stress in families.

Procedures

A list of the families active for at least four months and those who had been terminated within the last six months from FIPP was compiled by the FIPP Team Coordinators. An initial letter was sent by the Director of FIPP to each of the families explaining the study and asking if they would be willing to participate in the

Table 1

Examples of Questions From the
Questionnaire on Resources and Stress

All questions are answered true or false. The handicapped child's name is inserted in all blanks.

Scale 1: Excess Time Demands

1. When _____ is not well, I can't go out.
2. I have given up things I really want to do in order to care for _____.
3. Most of _____'s care falls on me.

Scale 2: Lack of Social Support

1. My family argues about how to care for _____.
2. Some members of my family don't like the way I do things.
3. Just talking about problems with close friends makes life easier.

Scale 3: Lack of Family Integration

1. _____ is cared for by all members of our family.
2. There is a lot of anger and resentment in our family.
3. Our family agrees on important matters.

Scale 4: Limits on Family Opportunities

1. The family does as many things together now as we ever did.
2. Other members of the family have to do without things because of _____.
3. A member of my family has had to give up education (or job) because of _____.

research survey. Verbal agreement to participate in the study was received from the families who had a telephone. Only one family refused to participate when contacted by telephone. A written permission form was included in each packet for the respondent to sign.

Upon agreement to participate, the Parent Trainer, or case coordinator for that family, took a packet of the instruments to the family on the next home visit. For those families which were no longer being served by FIPP, the packet, which included a stamped return envelope, was mailed.

The present study was conducted as one part of a larger FIPP study examining the relationship between social support available to families of handicapped preschoolers and (a) degree of stress among these families and (b) different aspects of child-parent interactions. There were five instruments, a permission form, a data sheet, and a reaction form in each packet. Demographic data were obtained from the data sheets and from the FIPP files.

In order to reduce any reactive effects from completing the questionnaires, order of completion was counterbalanced and parents were asked to complete only one scale a day over a week's time. The Parent Trainer then retrieved the packet of completed instruments during the next visit. If the packet was not returned after two visits, then a telephone call was made by the researcher to encourage completion of the instruments. Fifty-four packets which met the criteria for this study were received prior to the cut off date.

Once the instruments were received, the results were compiled. For the QRS, the score for each of the scales was totaled. The scores from the PRS for the three measures of role management were calculated as described earlier. Reliability of the computations and the transfer of data was checked. Average reliability of data summation and transfer was 99.3% for the QRS and 99.9% for the PRS.

Statistical Analyses

Role accumulation and stress. A median split of Role Accumulation scores was used to group the subjects according to low or high degree of role accumulation. The number of positive responses on each QRS subscale was used as the dependent measure. A Groups (Low vs. High Role Accumulation) by Parents (Mothers vs. Fathers), and a Groups (Low vs. High Role Accumulation) by Mothers (Mothers whose husbands did respond vs. Mothers whose husbands did not respond) ANOVA was used to analyze the data (See Table 2). Separate ANOVA were performed for each of the four QRS subscales.

Role congruence and stress. A median split of Role Congruence scores was used to group the subjects according to low or high degree of role congruence. The number of positive responses on each QRS subscale was used as the dependent measure. A Groups (Low vs. High Role Congruence) by Parent (Mothers vs. Fathers), and a Groups (Low vs. High Role Congruence) by Mothers (Mothers whose husbands did respond vs. Mothers whose husbands did not respond) ANOVA was used to analyze the data (See Table 3). Separate ANOVA were performed for each of the four QRS subscales.

Table 2

Role Accumulation by
Parents and Mothers

	Groups	
	Low	High
Parents		
Mothers	Low role accumulation by mothers	High role accumulation by mothers
Fathers	Low role accumulation by fathers	High role accumulation by fathers
Mothers		
Husbands Did Respond	Low role accumulation by mothers whose husbands did respond	High role accumulation by mothers whose husbands did respond
Husbands Did Not Respond	Low role acculumation by mothers whose husbands did not respond	High role accumulation by mothers whose husbands did not respond

Table 3

Role Congruence by
Parents and Mothers

	Groups	
	Low	High
Parents		
Mothers	Low role congruence by mothers	High role congruence by mothers
Fathers	Low role congruence by fathers	High role congruence by fathers
Mothers		
Husbands Did Respond	Low role congruence by mothers whose husbands did respond	High role congruence by mothers whose husbands did respond
Husbands Did Not Respond	Low role congruence by mothers whose husbands did not respond	High role congruence by mothers whose husbands did not respond

Role satisfaction and stress. A median split of Role Satisfaction scores was used to group subjects according to low or high degree of role satisfaction. The number of positive responses on each QRS subscale was used as the dependent measure. A Groups (Low vs. High Role Satisfaction) by Parent (Mothers vs. Fathers), and a Groups (Low vs. High Role Satisfaction) by Mothers (Mothers whose husbands did respond vs. Mothers whose husbands did not respond) ANOVA was used to analyze the data (See Table 4). Separate ANOVA were performed for each of the four subscales.

Table 4

Role Satisfaction by
Parents and Mothers

	Groups	
	Low	High
Parents		
Mothers	Low role satisfaction by mothers	High role satisfaction by mothers
Fathers	Low role satisfaction by fathers	High role satisfaction by fathers
Mothers		
Husbands Did Respond	Low role satisfaction by mothers whose husbands did respond	High role satisfaction by mothers whose husbands did respond
Husbands Did Not Respond	Low role satisfaction by mothers whose husbands did not respond	High role satisfaction by mothers whose husbands did not respond

Chapter IV

RESULTS

Preliminary Analyses

The mean scores of the subjects comprising the low and high role management groups were compared to determine if the groups in fact differed in terms of role accumulation, congruence, and satisfaction. The results of these anaylses are presented in Table 5. The two groups were found to differ significantly on all three role management scores. These results indicate that the low and high scores did significantly split the subjects into two groups on each of the role management measures.

Group membership was also compared across the three measures of role management. All three analyses were significant (See Table 6) which indicated that subjects who fell in the high group for one role measure would also be in the high group for the other two measures.

Preliminary analyses were performed on several sets of background data to determine if the low and high role management groups were homogeneous with regard to demographic and related background data. Table 7 presents the mean scores and standard deviations of the background variables examined. Statistical analyses revealed that the groups did not differ with respect to child's age, parental age, years of marriage, birth order, or the child's degree of

Table 5

Mean Scores and Standard Deviations (SD)
For Role Management Measures

Measures	Low			High			
	N	Mean	SD	N	Mean	SD	F
Role Accumulation	25	50.92	7.25	27	61.00	6.10	*30.77
Role Congruence	26	15.85	8.89	28	4.07	2.52	*45.26
Role Satisfaction	27	70.44	12.32	27	95.07	4.31	*96.04

*p<.001.

Table 6

Frequencies For
Group Membership

	Role Accumulation		
	High	Low	X^2
Role Congruence			
High	21	7	*10.68
Low	8	18	
Role Satisfaction			
High	22	6	*16.70
Low	6	20	

	Role Congruence		
	High	Low	X^2
Role Satisfaction			
High	21	6	*14.61
Low	7	20	

*p<.001.

Table 7

Mean Scores and Standard Deviations (SD) of Role Measures by Background Variables

Variables	Role Accumulation						Role Congruence						Role Satisfaction					
	Low			High			Low			High			Low			High		
	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD
Child's Age (Months)	25	37.00	15.43	29	36.10	36.10	26	40.61	16.91	28	32.71	15.87	27	38.63	17.00	27	34.41	16.45
Parent's Age (Years)	25	31.60	6.71	29	30.45	5.37	26	31.96	6.26	28	30.07	5.71	27	30.37	5.73	27	31.59	6.31
Years of Education	25	12.48	2.33	29	12.24	2.42	26	12.38	2.36	28	12.32	2.42	27	12.18	2.57	27	12.52	2.17
Years of Marriage	23	8.78	5.71	26	7.19	4.56	23	7.17	4.89	26	8,61	5.36	24	7.71	4.64	25	8.16	5.67
Birth Order	25	1.84	.75	29	1.65	1.14	26	1.77	.81	28	1.71	1.12	27	1.70	.67	27	1.78	1.22
Degree of Mental Retardation[a]	17	54.23	29.53	17	63.94	21.22	16	53.75	30.00	18	63.83	21.14	17	57.11	29.05	17	61.06	22.81

Note. No significant differences were found between the high and low role management groups on any of the measures.
[a]Degree of Mental Retardation=Mental Development Index or Stanford-Binet IQ.

mental retardation. The degree of mental retardation was measured by either a Mental Development Index (Bayley, 1965) or a Stanford-Binet IQ (Terman, Merrill & Thorndike, 1972). Similarly, no significant difference was found between the groups in terms of the child's sex, father's occupation, or the type of child's disability (See Table 8). However, mother's occupation was significantly related to role congruence and role accumulation scores. Mothers who worked outside the home reported performing more roles than did mothers who were primarily housewives. The data also showed that mothers who worked outside the home wanted fewer changes in who performs various roles than mothers who were housewives.

Primary Analyses

The results of the primary analyses are shown in Table 9. Only one significant difference was found between the high and low role accumulation groups. Parents who reported performing few roles indicated less family integration. When the parents performed many roles, they felt their families were more integrated.

Two significant differences were found between the high and low role congruence groups. Low agreement on who should perform roles was significantly related to less family integration. When parents reported low agreement on who should perform roles, they also indicated fewer family opportunities.

Significant differences were found between high and low role satisfaction groups on all four of the QRS scales. Parents who expressed low satisfaction with how roles were performed indicated high demands on their time. Less satisfaction in role performance

Table 8

Frequencies of Role Measures
by Background Variables

Variables	Role Accumulation Low	Role Accumulation High	X^2	Role Congruence Low	Role Congruence High	X^2	Role Satisfaction Low	Role Satisfaction High	X^2
Child's Sex									
Male	16	22	.28	18	20	.12	18	20	1.13
Female	8	8		8	8		10	6	
Mother's Occupation									
Housewife	14	7	*6.23	14	7	**8.63	13	8	1.88
Other[a]	3	10		2	11		5	8	
Father's Occupation									
Professional/Manager	5	5	1.25	5	5	.4	6	4	.8
Sales/Service	3	2		2	3		2	3	
Laborer	4	1		3	2		2	3	
Type of Disability									
Motor Impairment	5	7	.52	6	6	1.91	4	8	2.24
Mental Retardation/ Developmentally Disabled	6	5		3	8		7	4	
At-Risk	6	5		6	5		6	5	

[a]Other=Professional, Manager, Sales and Laborer occupations.
*p<.05.
**p<.001.

Table 9

Mean Scores and Standard Deviations (SD) For
Role Measures, Parents and Mothers

	Role Accumulation					Role Congruence					Role Satisfaction				
	Low (N=25)		High[a] (N=29)			Low (N=26)		High (N=28)			Low (N=27)		High (N=27)		
Measures	Mean	SD	Mean	SD	F	Mean	SD	Mean	SD	F	Mean	SD	Mean	SD	F
Excess Time Demands	5.16	2.49	4.76	2.23	.39	5.38	2.50	4.53	2.15	2.02	5.81	2.67	4.07	1.57	**9.80
Lack of Social Support	3.80	1.47	3.27	1.39	2.32	3.65	1.47	3.39	1.42	.44	3.96	1.50	3.07	1.24	*5.67
Lack of Family Integration	2.88	1.88	1.76	1.96	*4.57	2.88	2.18	1.71	1.63	*5.02	3.04	2.14	1.52	1.50	**9.02
Limits on Family Opportunities	1.60	1.98	.79	1.54	2.74	1.92	2.17	.46	.92	**10.30	1.96	2.10	.37	.88	**12.73

[a]High role accumulation indicates the performance of many roles.
*p<.05.
**p<.001.

was also related to low social support for these parents. Parents who indicated low satisfaction in role performance also reported less family integration and few family opportunities.

Only one significant difference was found between mothers and fathers (See Table 10). This was in the area of excess time demands. Mothers indicated having more time demands than did the fathers. As the analyses shows in Table 10, no significant difference was found between the mothers whose husbands had completed the questionnaires vs. mothers whose husbands had not completed the questionnaires.

Table 10

Mean Scores and Standard Deviations (SD)
For Parents and Mothers

	Parents					Mothers				
	Mothers (N=34)		Fathers (N=20)			Husbands Did Respond (N=20)		Husbands Did Not Respond (N=14)		
	Mean	SD	Mean	SD	F	Mean	SD	Mean	SD	F
Excess Time Demands	5.59	2.44	3.85	1.72	*7.83	5.40	2.37	5.86	2.60	.28
Lack of Social Support	3.29	1.45	3.90	1.37	2.31	3.10	1.48	3.57	1.40	.91
Lack of Family Integration	2.50	2.06	1.90	1.83	1.15	1.95	1.90	3.28	2.09	3.74
Limits on Family Opportunities	1.18	1.66	1.15	2.03	2.75	1 05	1.96	1.36	1.15	.27

*p.<.001.

Chapter V

DISCUSSION

The purpose of this study was to examine how role management related to levels of stress in families with preschool handicapped children. The independent variable, role management, was divided into three components: role accumulation, role congruence, and satisfaction with role performance. These indicators of role management were compared with four measures of stress in families.

The discussion of stress and some of the reflections of stress is most beneficial when placed in the framework of an ecological model. Each of the relationships between the independent measure, role management, and the dependent measure, stress, is most accurately understood when viewed as part of the total environment. They are only two of numerous ecological units which influence families with a handicapped child. When attempting to keep handicapped children in the home, it is crucial to identify the causes of stress and sources of support for each family.

The research questions to be answered were:

1. What is the relationship between reported role accumulation and levels of stress?
2. What is the relationship between reported role congruence and levels of stress?
3. What is the relationship between reported satisfaction with role performance and levels of stress?

Role Accumulation

Only one of the stress measures, Lack of Family Integration, was significantly related to role accumulation. This suggests that people who perform many roles perceive their families as being more integrated. Conversely, those parents who reported performing few roles indicated their families were less integrated. This particular finding is difficult to explain inasmuch as it related specifically to how one views performing many roles. If the respondents consider filling many roles as a way of being highly involved in the family, then they will report more family integration. However, if the persons resent performing many roles, then they interpret this as less integration in the family. The missing piece of information is how they feel about the number of roles they perform.

Role Congruence

An indication of contentment with the number of roles performed came from the measure of role congruence. This measures the difference in who does the role now and who they would like to do it. Role congruence was significantly related to less family integration and fewer family opportunities. The direction in both of these cases was as predicted. Parents less contented with who performs different roles reported less family integration. It is logical that parents discontented with who performs the roles would also feel the family was not working together.

The relationship between congruence of roles and family opportunities is such that when parents are not happy with who performs different roles, they also reported having few opportunities for

themselves and their family. This suggests that people who are discontent with who performs the role will have a limited view of opportunities. Though there is no significant relationship between role congruence and excess time demands or lack of social support, the results were in the predicted direction.

Role Satisfaction

All four of the dependent variables were significantly related to how well the respondents perceived the roles were being performed. Low satisfaction with the performance of roles related to high excess time demands, poor social support, less family integration, and limits on family opportunities. Parents who perceive many time demands probably do not sense they do a good job performing the roles. The lack of social support is more complicated than just the lack of satisfaction with role performance. It may be that people who feel they do not perform roles well need more social supports. Bristol (1979) found that the mother's abilities to cope with stress were related to the amount of personal support they received.

The high dissatisfaction with how roles are being performed may be one of the issues which leads to poor family integration. If roles are being performed inadequately, then the family is not functioning well. The poor functioning of the family will probably lead to fewer opportunities for its members.

It is interesting that how well roles are performed was more clearly related to the stress measures, than the number of roles performed. This may suggest that people are not necessarily

unhappy when they must perform many roles, but will be dissatisfied if they judge the performance of the roles as poor.

All of these relationships point to the possibility that when there are problems with role management, especially satisfaction with role performance, then levels of stress appear. The inability to manage roles may support the findings of Lewis et al. (1976) which suggest that less healthy families were not as skillful in negotiating conflict. Not being able to manage roles may lead families to experience more time demands, less social support, less family integration, and few family opportunities. The energy which might have gone into some of these activities will instead be used in trying to get the jobs in the family accomplished at a satisfactory level.

Since this study did not attempt to establish cause and effect between role management and stress, it is possible that the direction of the relationship is reversed. An alternative hypothesis would suggest that high stress creates problems in role management. More time demands, less social support, less family integration, and few family opportunities may cause difficulties in the area of role management. Parents find that these stresses keep them from performing different roles at satisfactory levels, and they are unhappy with the management of roles.

Background Variables

The idea that management of roles does relate to the amount of stress a family experiences is supported by the data gathered in this study. When background variables were examined, the only

factor which seemed to affect these findings was mother's occupation. Mothers who worked outside the home reported performing more roles and were more content with who performed different roles than the housewives. The fact that mothers who work outside the home do more roles is not surprising. It probably indicates that these mothers continued to perform household and child care roles, as they added new roles which came from working outside the home. It is interesting that they performed more roles, yet they wanted fewer changes in who should execute the roles. There was no significant difference in their evaluation of how well the roles were performed.

Much of the literature (Holroyd & McArthur, 1976; Bristol, 1979; Korn et al., 1978) discussed the type and degree of disability as factors in the amount of stress on the family. This study found that the high and low role management groups were homogenous in regard to the types of handicap and the degree of mental retardation. Cross (1980) also reported no significant difference in stress scores or satisfaction in role performance when he controlled for the degree of severity of the child's impairment. Perhaps there are other factors involved than just the type of handicap. It would seem that the amount of formal or informal support and/or resources available to a family would greatly influence the amount of stress perceived. If a strong social stigma is attached to even a mild handicap, then the family may feel a lot of stress unless they have other support systems. A family with a severely handicapped child may feel little stress if they are involved in a strong support network.

Differences Between Mothers and Fathers

The only difference found was that mothers felt they had higher demands on their time than did fathers. The questions in this section indicated that mothers often must limit their activities outside the home and do not have enough time for themselves. This finding is probably a reflection of what Nye (1976) refers to as a "traditional" division of labor. Mothers are the primary care takers of the child and often feel the major impact of the child on their time. This division of labor is probably typical for the area from which the sample was taken. These families are from mainly small communities in western North Carolina, an area which generally reflects conservative values and standards.

Major Implications

This section will present major implications of this study for both research and service delivery.

Research implications. Several interesting research questions arose from this study. One question already alluded to involves role accumulation and role congruence for mothers who work outside the home. These mothers performed many roles and were content with this division of labor. This finding may indicate that these mothers feel they perform the roles well and do not need help. Another interpretation is that they do not feel they will get help and have given up asking for it.

Exploratory research with mothers who have a handicapped child and who work outside the home is needed to find out specifically what their problems and needs are in managing these various roles.

Since it will be necessary to identify the different variables which provide support and cause stress, several case studies would be the best way to initiate research in this area. Once some of the variables have been identified, then a larger study can be done to see if the relationships will hold.

Another aspect of interest is how parents interpret satisfaction of role performance. Does satisfaction simply mean that they do not have to do the role or is there a true quality judgment about the way the role is performed? It may be that as long as they do not have to perform the role, they are happy with how it is done. In order to determine their interpretations, interviews are needed to explore their translation of role satisfaction.

The Parent Role Scale can be divided into child care and household roles. These two divisions need to be examined in terms of stress factors. Is one set of responsibilities more stressful than the other? Do the two types of roles suggest stress in different areas? Or does one area reflect stress more? There may also be differences between mothers and fathers. It may be that the sex of the parent will be related to the stress experienced between child care or household roles. Are fathers just as comfortable with either set of roles? All of these factors need to be investigated.

In order to provide families with ways of solving role management problems, more research is needed in examining how families with few problems are able to manage roles and keep stress levels low. Although researchers (Lewis et al., 1976; Cross, 1980) have begun to examine the nature of healthy families, further study is

needed into how families adapt to a handicapped child and continue to function as a healthy unit. A longitudinal study which examines multiple variables of support and stress in families with handicapped children would begin to establish some patterns in family functioning. It would also allow for the identification of stages through which families pass and any different coping patterns used in these various stages.

Service implications. This study was an attempt to add information to an ecological model of family functioning. Most handicapped children live in a family system and these families interact with members of a larger environment. If we take the position that it is good for handicapped children to remain in their families, then it is important to examine all of the factors which help facilitate and influence this. Interventions must be designed to go beyond the child to the total family unit.

Stress on families with handicapped children has been documented (Tavormina & Kralj, 1975; Bristol, 1979). Now it is important to begin to identify possible causes and results of stress. Results of this study demonstrated the possible relationship between how the family manages various roles and stress. Although a cause and effect relationship can not be established from this study, how satisfied parents are with the performance of the roles seems related to levels of stress.

Once other ecological factors which contribute to support and stress have been identified, then practitioners will have an inventory of items they can discuss with families. This inventory could

be used as part of an initial intake procedure or with families who have the potential for these problems. It will help the practitioner and family begin to examine areas beyond the child which may be causing them stress.

Identification of the factors which cause stress is only the first step. Next comes the location of support for each family. If the necessary support is not part of the family's environment, then a way of providing this must be established. The establishment of support will involve more than training the child. The service model will have to expand to include informal parent groups, informal networks of parent contacts, educational materials, respite care, access to professionals in various fields, and identification of other agencies, only to name a few.

Conclusion

The evidence from this study indicated that there is a relationship between satisfaction with role performance and levels of stress in families with preschool handicapped children. It appears that how well roles are performed is more significantly related to stress than the number of roles performed or who they would like to perform the roles.

These results suggest that both researchers and practitioners need to look beyond the child when attempting to identify factors which create or reflect stress. If the focus remains only on the handicapped child, then many support and stress variables will not be examined. Only by acknowledging the complexity of the systems in which families function will practitioners be able to identify

and meet the needs of the families they serve. Families are involved in a web of interactions which must be acknowledged and included in any attempt to identify and solve their individual problems. Each family must be dealt with individually as they work with practitioners in attempting to solve the problems which will enable them to keep their child in the home. No longer will simplistic explanations and solutions solve the problems faced by these families.

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APPENDIX A

Questionnaire on Resources and Stress

Code _____ Relationship to Child _____

QUESTIONNAIRE ON RESOURCES AND STRESS

This questionnaire deals with your feelings and thoughts about your child enrolled in the Family, Infant and Preschool Program. There are many blanks on the questionnaire. Imagine your child's name filled in on each blank. THERE ARE NO RIGHT OR WRONG ANSWERS. Give your honest feelings and opinions.

Please answer all the questions even if they do not seem to apply. If it is difficult to decide TRUE or FALSE, answer in terms of what you or your family feel or do most of the time.

The questions sometimes refer to a child older than your own, or someone who has problems your child does not have. In any case, all the questions can be answered TRUE or FALSE even then.

Because this questionnaire is so long, do not try to answer all the questions at one time. It is best to answer them over several days.

Code _____ Relationship to Child _____

QUESTIONNAIRE ON RESOURCES AND STRESS

Circle the response (True or False) that best reflects your feelings and opinions. Please answer all questions. Imagine your child's name filled in on each blank.

1. True False _____ demands that others do things for him/her more than is necessary.
2. True False _____ understands the idea of time.
3. True False Because _____ is the kind of person he/she is, he/she can handle his/her situation better than another person could.
4. True False _____ is cared for equally by all members of our family.
5. True False It will take us three years or more to pay off our debt.
6. True False A member of my family has had to give up education (or a job) because of _____.
7. True False One of the things I appreciate in _____ is he/she is independent.
8. True False Members of the family share in the care of _____.
9. True False _____ would not resent being left at home while the family went on vacation.
10. True False Members of our family praise each other's accomplishments.
11. True False _____ has a pleasing personality.
12. True False I do not attend very many meetings (PTA, church, etc.).
13. True False I know _____'s condition will improve.
14. True False _____ does not have problems with seeing or hearing.
15. True False Even if people don't look at _____, I am always wondering what they might think.
16. True False I take on responsibility for _____ because I know how to deal with him/her.

17. True False _____ has some unusual habits which draw attention.

18. True False In our house the whole family eats dinner together.

19. True False The doctor sees _____ at least once a month.

20. True False I usually do not have to take _____ with me when I go out.

21. True False There is more than one wage-earner in our family.

22. True False _____ is a very capable, well functioning person despite his/her other problems.

23. True False I always watch to make sure _____ does not do physical harm to himself/herself or others.

24. True False The special opportunities needed by _____ are available in our community.

25. True False Our house is confortably arranged to meet _____'s needs without making it difficult for other members of the family.

26. True False Money from the government or an organization pays for part of our medical costs.

27. True False _____ would be in danger if he/she could get out of the house or yard.

28. True False I feel that our family situation will get better.

29. True False Medicine does not have to be given to _____ at a set time.

30. True False _____ doesn't communicate with others of his/her age group.

31. True False People who don't have the problems we have don't have the rewards we have either.

32. True False Other members of the family have to do without things because of _____.

33. True False _____'s problems or illness do not stand in the way of our family progress.

34. True False When others are around _____ I cannot relax; I am always on guard.

35. True False If _____ were more pleasant to with it would be easier to care for him/her.

36. True False Thinking about the future makes me sad.

37. True False Much of the time I think about _____ dying.

38. True False If I knew when _____ would die I wouldn't worry so much.

39. True False I don't worry too much about _____'s health.

40. True False Our family agrees on important matters.

41. True False Professionals (nurses, etc.) in an institution would understand _____ better than I do.

42. True False When _____ is not well, I can't go out.

43. True False I am afraid that by limiting _____'s activities he/she will not develop on his/her own.

44. True False Our family's income has dropped over the past 5 years.

45. True False The constant demands for care for _____ limit growth and development of someone else in our family.

46. True False _____ feels that I am the only one who understands him/her.

47. True False In his/her own way _____ brings as much pleasure to our family as the other members.

48. True False I worry about what will happen to _____ when I can no longer take care of him/her.

49. True False I think in the future _____ will take up more and more of my time.

50. True False I am able to leave _____ alone in the house for an hour or more.

51. True False I fear the day when other members of the family leave home and I am left alone with _____.

52. True False It would be better for _____ if our house could be remodeled.

53. True False A counselor or a teacher sees _____ at least once a month.

54.	True	False	I get out of the house to do something interesting at least once a week.
55.	True	False	I am very careful about asking _____ to do things which might be too hard for him/her.
56.	True	False	The attitude of our family makes it impossible for _____ to live with us any longer.
57.	True	False	I would rather be caring for _____ than doing some other kind of work.
58.	True	False	_____ is limited in the kind of work he/she can do to make a living.
59.	True	False	I have accepted the fact that _____ might have to live out his/her life in some special setting (i.e., hospital, institution, foster home).
60.	True	False	I have given up things I have really wanted to do in order to care for _____.
61.	True	False	My family argues about how to care for _____.
62.	True	False	_____ is able to fit into the family social group.
63.	True	False	Some members of my family don't like the way I do things.
64.	True	False	I would not want the family to go on vacation and leave _____ at home.
65.	True	False	At times I fear _____ will not be able to function in society if he/she is out of our house.
66.	True	False	It is difficult for me to stand back and watch _____'s condition get worse.
67.	True	False	In the future our family's social life will suffer because of increased responsibilities and financial pressure.
68.	True	False	It doesn't make any difference to _____ if he/she is at home or in a hospital.
69.	True	False	_____ knows the difference between strangers and friends.
70.	True	False	I am afraid that other members of the family will be hurt because they are related to _____.

71. True False There is no way we can possibly keep _____ in our house.

72. True False People should take care of their own.

73. True False One of us has had to pass up a chance for a job because _____ could not be removed from a clinic or a special school, etc.

74. True False I would rather help _____ do something than have him/her fail and feel badly.

75. True False _____ has always lived with our family.

76. True False I cannot manage _____.

77. True False Sometimes I avoid taking _____ out in public.

78. True False _____ is on a special diet.

79. True False Many people simply don't understand what it is like to live with _____.

80. True False Every member of our family has had to do without things because of money spent on _____.

81. True False _____ can feed himself/herself.

82. True False I tend to do things for _____ that he/she can do himself/herself.

83. True False When we go on vacation, I'm not afraid to leave _____ for any length of time.

84. True False As the time passes I think it will take more and more to care for _____.

85. True False I belong to organizations which help with problems I have with _____.

86. True False There have been serious emotional problems for someone in our family.

87. True False Our relatives have been very helpful.

88. True False We have discussed what will happen when _____ dies.

89. True False It is easier for me to do something for _____ than to let him/her do it himself/herself and make a mess.

90.	True	False	_____ is easy to manage most of the time.
91.	True	False	I don't think that _____ depends too much on me or other members of the family.
92.	True	False	It is not necessary for _____ to go up or down steps in our house.
93.	True	False	I feel that I must protect _____ from the remarks of children.
94.	True	False	We can afford to pay for the care _____ needs.
95.	True	False	Just talking about problems with close friends makes life easier.
96.	True	False	I can never leave the house because of _____.
97.	True	False	I am happy when I watch the development and achievements of _____.
98.	True	False	It bothers me that _____ will always be this way.
99.	True	False	No one in our family drinks alcohol too much.
100.	True	False	The community is used to people like _____.
101.	True	False	_____ uses special equipment because of his/her handicap.
102.	True	False	_____ has a handicap which prevents him/her from improving.
103.	True	False	_____ is sometimes too sexual.
104.	True	False	_____ has a lot of pain.
105.	True	False	I feel tense whenever I take _____ out in public.
106.	True	False	_____ is easy to live with.
107.	True	False	The doctor sees _____ at least once a year.
108.	True	False	_____ eats his/her meals with other members of the family.
109.	True	False	Wheelchairs or walkers have been used in our house.

110.	True	False	An electricity failure would endanger _____,s life or health.
111.	True	False	Caring for _____ has been a financial burden for our family.
112.	True	False	_____ made a good income at one time.
113.	True	False	Some friends are very helpful when it comes to _____.
114.	True	False	I worry that _____ may sense that he/she does not have long to live.
115.	True	False	_____ will not do something for himself/herself if he/she knows someone will do it for him/her.
116.	True	False	I can go visit with friends whenever I want.
117.	True	False	Members of the family show no interest in what happens to _____.
118.	True	False	We enjoy _____ more and more as a person.
119.	True	False	We have changed our house because of _____.
120.	True	False	Taking _____ on a vacation spoils pleasure for the whole family.
121.	True	False	The family does as many things together now as we ever did.
122.	True	False	_____ knows his/her own address.
123.	True	False	_____ gets along very well with others.
124.	True	False	_____ is aware of who he/she is (for example, male 14 years old).
125.	True	False	_____ prevents any communication within our family.
126.	True	False	Someone in our family turns against _____ when his/her friends are around.
127.	True	False	Sometimes I need to get away from the house.
128.	True	False	I get upset with the way my life is going.
129.	True	False	Sometimes I feel very embarrassed because of _____.

130. True False Having to care for _____ has enriched our family life.

131. True False Neighbors want us to move because of _____.

132. True False I respect _____'s judgment about what he/she can do.

133. True False _____ doesn't do as much as he/she should be able to do.

134. True False Our family has been on welfare.

135. True False We have discussed what will happen if _____ lives longer than we do.

136. True False _____ is truly accepted by the family.

137. True False A bed that raises and lowers has made things easier.

138. True False We take _____ along when we go out.

139. True False It makes me feel good to know I can take care of _____.

140. True False Others do for _____ what he/she could do for himself/herself.

141. True False Because of _____ our family has never enjoyed a meal.

142. True False I hate to see _____ try to do something and fail.

143. True False _____ is accepted by other members of the family.

144. True False I fear _____ might get hurt while playing games or sports.

145. True False It is difficult to communicate with _____ because he/she has difficulty understanding what is being said to him/her.

146. True False _____ spends time at a special day center or in special classes at school.

147. True False _____ is very anxious most of the time.

148. True False _____'s health is not getting worse.

149.	True	False	There is no special government program to help _____.
150.	True	False	I have no time to give the other members of the family.
151.	True	False	Our family is quite religious.
152.	True	False	In our family _____ takes an active part in family affairs.
153.	True	False	There are many places where we can enjoy ourselves as a family when _____ comes along.
154.	True	False	It is hard to think of enough things to keep _____ busy.
155.	True	False	_____ is over-protected.
156.	True	False	Our family income is more than average.
157.	True	False	Some of our family does not bring friends into the home because of _____.
158.	True	False	I try to get _____ to take care of himself/herself.
159.	True	False	Caring for _____ gives one a feeling of worth.
160.	True	False	We have discussed his/her death with _____.
161.	True	False	_____ is able to take part in games or sports.
162.	True	False	One of us has had to pass up a chance for a job because _____ could not be left without someone to watch him/her.
163.	True	False	We think _____ will live longer in an institution.
164.	True	False	_____ has too much time on his/her hands.
165.	True	False	There is an organization for families who share our problems.
166.	True	False	I am disappointed that _____ does not lead a normal life.
167.	True	False	We spend up to 25 percent of our income on medical care (or care for _____).

168. True False Time drags for _____ -- especially free time.

169. True False I worry about how our family will adjust after _____ is no longer with us.

170. True False The part that worries me most about _____ going on his/her own is his/her ability to make a living.

171. True False _____resents being treated as a handicapped person.

172. True False _____ can't pay attention very long.

173. True False I worry about what will be done with _____ when he/she gets older.

174. True False If _____ were healthier it would be easier to go away for a holiday.

175. True False Compared to others, we spend alot of money on medical costs.

176. True False I get almost too tired to enjoy myself.

177. True False _____ has things to entertain him/her (TV, radio) in his/her room.

178. True False We owe a great deal of money.

179. True False _____ is depressed most of the time.

180. True False If I were healthier, it would be easier to care for _____.

181. True False Most persons in public places indicate they don't want _____ around.

182. True False _____ can get around the neighborhood quite easily.

183. True False _____ wants more freedom than he/she has.

184. True False One of the things I appreciate about _____ is his/her confidence.

185. True False I don't mind when people look at _____.

186. True False Whenever I leave the house I am worried about what's going on at home.

187.	True	False	In our family _____ plays as an important role as other members.
188.	True	False	_____ will never be any brighter than now.
189.	True	False	One of the things I appreciate about _____ is his/her ability to recognize his/her own limits.
190.	True	False	I believe _____ should go places as often as others in the family.
191.	True	False	I am not embarrassed when others question me about _____'s condition.
192.	True	False	There is a lot of anger and resentment in our family.
193.	True	False	If _____ could get around better we would do more as a family.
194.	True	False	Our family has managed to save money or make investments.
195.	True	False	We own or are buying our own home.
196.	True	False	Information and encouragement is available to those who seek it.
197.	True	False	We get special funds because of _____'s problem.
198.	True	False	One of the things I enjoy about _____ is his/her sense of humor.
199.	True	False	We can have no luxuries.
200.	True	False	I have enough time to myself.
201.	True	False	_____ is able to go to the bathroom alone.
202.	True	False	I am afraid _____ will not get the individual attention, affection, and care that he/she is used to if he/she goes somewhere else to live.
203.	True	False	I have too much responsibility.
204.	True	False	No member of the family pities _____ too much.
205.	True	False	_____ cannot remember what he/she says from one moment to the next.

206. True False _____ is better off in our home than somewhere else.

207. True False _____ can describe himself/herself as a person.

208. True False Others in the family should help care for _____.

209. True False A nurse sometimes works in our home.

210. True False Relatives have done more harm than good when it comes to _____.

211. True False I am afraid that as _____ gets older it will be harder to manage him/her.

212. True False It is easy to keep _____ entertained.

213. True False It makes me feel worthwhile to help _____.

214. True False _____ wants to do things for himself/herself.

215. True False In the future _____ will be more able to help himself/herself.

216. True False _____ needs a walker or a wheelchair.

217. True False I have become more understanding in my relationships with people as a result of _____.

218. True False The constant demands to care for _____ limit my growth and development.

219. True False _____ cannot get any better.

220. True False _____ is very tense in strange surroundings.

221. True False It is easy to communicate with _____.

222. True False I feel sad when I think of _____.

223. True False Our family should do more together.

224. True False I have had to give up a chance for a job because of _____.

225.	True	False	_____ accepts himself/herself as a person.
226.	True	False	Outside activities would be easier without _____.
227.	True	False	Our relatives give us much help.
228.	True	False	I enjoy church.
229.	True	False	Caring for _____ puts a strain on me.
230.	True	False	I often worry about what will happen to _____ when I no longer can take care of him/her.
231.	True	False	_____ can use the bus to go wherever he/she wants.
232.	True	False	People can't understand what _____ tries to say.
233.	True	False	If it were not for _____ things would go better.
234.	True	False	I feel that _____ would prefer a professional (nurse, day care helper, etc.) to care for him/her rather than a member of our family.
235.	True	False	Some members of the family resent _____.
236.	True	False	Members of our family get to do the same kinds of things other families do.
237.	True	False	_____ embarrasses others in our family.
238.	True	False	My happiness goes up and down with _____'s behavior.
239.	True	False	_____ uses the phone frequently.
240.	True	False	_____ has many things to keep him/her busy.
241.	True	False	Sometimes the demands _____ makes drive me out of my mind.
242.	True	False	I had high hopes for _____'s future.
243.	True	False	_____ could do more for himself/herself.

244.	True	False	My family understands the problems I have.
245.	True	False	It is easy to do too much for _____.
246.	True	False	_____ appreciates the interest others show in him/her.
247.	True	False	It is easier for our family to do things with people we know than with strangers.
248.	True	False	I am pleased when others see my care of _____ is important.
249.	True	False	We can hardly make ends meet.
250.	True	False	_____ rarely has nightmares.
251.	True	False	I don't try to shelter _____ from life's difficulties.
252.	True	False	Members of my family are able to discuss personal problems.
253.	True	False	I often have the desire to protect _____.
254.	True	False	I am as healthy as I ever was.
255.	True	False	_____ does not dress right.
256.	True	False	Most of _____'s care falls on me.
257.	True	False	No one can ever understand what I go through.
258.	True	False	We have household help (cleaning woman, nurse, etc.)
259.	True	False	It is fortunate how _____ has adjusted to life.
260.	True	False	_____ accepts his/her handicap.
261.	True	False	_____ has his/her own room.
262.	True	False	_____ is very irritable.
263.	True	False	We have lost most of our friends because of _____.

264.	True	False	_____ has an attractive, clean appearance.
265.	True	False	_____ can ride a bus.
266.	True	False	_____ will always be a problem to us.
267.	True	False	_____ is able to express his/her feelings to others.
268.	True	False	It is easy for me to relax.
269.	True	False	_____ has to use a bedpan or a diaper.
270.	True	False	I rarely feel blue.
271.	True	False	We have good laundry facilities at home.
272.	True	False	_____ can walk without help.
273.	True	False	_____ needs help in the bathroom.
274.	True	False	I have chances to carry on interests outside the home.
275.	True	False	It bothers me to see _____ in pain.
276.	True	False	Every cloud has a silver lining.
277.	True	False	I like myself as a person.
278.	True	False	I am worried much of the time.
279.	True	False	_____ has a strongly defiant personality.
280.	True	False	Because _____ uses special equipment and facilities, it is difficult to take him/her out.
281.	True	False	One of the things I appreciate about _____ is his/her sensitivity to others.
282.	True	False	Others have offered to share the load in caring for _____.

283. True False _____ likes to follow the same schedule all the time.

284. True False _____'s needs come first.

285. True False _____ attracts attention.

APPENDIX B

Parent Role Scale

Code: _____ Relationship to Child _____

PARENT ROLE SCALE

This questionnaire deals with the way parent responsibilities are shared within different families. This information is useful for learning how different families adjust to both the joys and strains of family living.

The jobs listed in this questionnaire are those found in all families regardless of who does them. We would like your opinion as to:

A. Who now does each job in your family?

B. Who you would like to see do it?

C. How satisfied you are with the way it is being done now?

THERE ARE NO RIGHT OR WRONG ANSWERS. Give your honest opinions and feelings. Please answer all three parts to each question.

Instructions

Please circle 1 (one) answer for A, 1 (one) answer for B, and 1 (one) answer for C in each question. If someone helps you with a job, please write in that person's relationship to you in the blanks provided.

1. WHO HELPS THE CHILD(REN) WITH THEIR HOMEWORK, READS TO OR GENERALLY TALKS TO THE CHILD(REN)?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

2. WHO GIVES REWARD OR PUNISHMENT TO THE CHILD(REN) AS APPROPRIATE?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

3. WHO TAKES CARE OF THE CHILD(REN) WHEN THEY ARE SICK OR UPSET?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

4. WHO TAKES THE CHILD(REN) PLACES WHEN THEY CAN'T GET THERE THEMSELVES?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

5. WHO HELPS THE CHILD(REN) PICK OUT THEIR CLOTHES?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

6. WHO DECIDES WHAT KINDS OF TRIPS THE FAMILY TAKES AS WELL AS WHERE AND WHAT THE CHILD(REN) PLAY?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

7. WHO PROVIDES FINANCIALLY FOR THE FAMILY?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

8. WHO DECIDES WHERE THE FAMILY'S MONEY WILL BE SPENT?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

9. WHO PROTECTS FAMILY MEMBERS WHEN THEY ARE IN DANGER?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW.
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

10. WHO KEEPS RECORDS OF THE FAMILY'S SPENDING?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

11. WHO BUYS THE GROCERIES?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

12. WHO COOKS THE MEALS FOR THE FAMILY?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

13. WHO TAKES CARE OF THE YARD OR THE AREA OUTSIDE THE HOUSE OR APARTMENT?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

14. WHO TAKES CARE OF THE INSIDE OF THE HOME OR APARTMENT?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

15. WHO FIXES APPLIANCES OR EQUIPMENT IN OR AROUND THE HOUSE OR APARTMENT?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT'S BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

16. WHO HELPS FAMILY MEMBERS TO DECIDE WHAT IS RIGHT AND WRONG?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT'S BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

17. WHEN COMPANY IS COMING, WHO TAKES THE RESPONSIBILITY FOR GETTING THE HOUSE AND FAMILY READY?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

18. WHO DEALS WITH ANY OUTSIDE AGENCIES SUCH AS SCHOOL, CHURCH, SOCIAL AND MEDICAL SERVICES, ETC.?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

19. WHO KEEPS IN TOUCH WITH NEIGHBORS AND FRIENDS?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

20. WHEN SOMEONE IN THE FAMILY HAS PROBLEMS, WHO DO THEY TALK TO?

A. WHO DOES THIS NOW?	B. WHO WOULD YOU LIKE TO HAVE DO IT?	C. HOW SATISFIED ARE YOU WITH THE WAY IT's BEING DONE NOW?
1. I do it alone.	1. I'd like to do it alone.	1. Very dissatisfied.
2. I do it with help from my husband.	2. I'd like to have help from my husband.	2. Somewhat dissatisfied.
3. I share it equally with my husband.	3. I'd like to share it equally with my husband.	3. Neither satisfied nor dissatisfied.
4. My husband does it with help from me.	4. My husband would do it with help from me.	4. Moderately satisfied.
5. My husband does it alone.	5. My husband would do it alone.	5. Very satisfied.

APPENDIX C

Initial Letter to Families

STATE OF NORTH CAROLINA
DEPARTMENT OF HUMAN RESOURCES
DIVISION OF MENTAL HEALTH SERVICES

WESTERN CAROLINA CENTER
ENOLA ROAD
MORGANTON, N C 28655

J IVERSON RIDDLE, M.D.
Director

Family, Infant and Preschool Program

Dear Parents:

During the past several years the Family, Infant and Preschool program has expanded its service-delivery efforts in order to be more responsive to the needs of the families of the children we serve. As one means to insure that we are doing so, our program is about to begin a research survey to learn more about families so that we can better plan our service-delivery efforts. We hope you will help us by participating in this project.

The purpose of this study is to see how support and help available to parents of very young children (both handicapped and nonhandicapped) helps the family in terms of dealing with the day-to-day demands and stresses of raising an infant or preschool aged child. Participation in the project will involve filling-out five questionnaires dealing with different aspects of family life and raising a child. We are asking that both fathers and mothers complete the forms. In single parent households, only the parent who cares for the child will need to complete the questionnaires. Your participation in this study is extremely important. The more we are able to learn about families of young children, the better we will be able to meet the needs of your child and family.

All information obtained in this study will be held in the strictest confidence. The information is coded so that your family's identity is always protected. No information will be shared with anyone who is not involved in conducting this survey. Your participation is voluntary, and you may withdraw your consent to participate at anytime. At the completion of the study, you will be given a written summary of the findings.

I hope you will consider participating in this project. We are sending this letter both to families currently enrolled in the Family, Infant and Preschool Program and to families whose children have been recently terminated from the program. Within the next several days you will be receiving a phone call from Ms. Carol Trivett who is helping with the study. She will explain the project more fully to you and answer any questions you may have. In the meantime, if there are any questions I can help with, please feel free to give me a call.

Sincerely,
Carl J. Dunst

Dr. Carl J. Dunst
Director, Family, Infant and
Preschool Program

"Esse Quam Videri"

pc

APPENDIX D

Consent Form

STATE OF NORTH CAROLINA
DEPARTMENT OF HUMAN RESOURCES
DIVISION OF MENTAL HEALTH SERVICES

WESTERN CAROLINA CENTER
ENOLA ROAD
MORGANTON, N. C. 28655

J. IVERSON RIDDLE, M.D.
Director

INFORMED CONSENT FORM

I understand that the purpose of this study is to see how support and help available to parents of young children helps the family in terms of dealing with the day-to-day demands and stresses of raising an infant or preschool aged child. I also understand that I will be completing five questionnaires and filling-out a background information form as part of my participation in this study. It is expected that the information obtained from this study will potentially benefit the Family, Infant and Preschool Program in better planning services for the children and families served.

I understand that my participation in this project is voluntary; that all information is coded to protect my family's identity; and that I may withdraw my consent to participate at any time. I also understand that neither my withdrawal of consent nor my opinions and feelings expressed in this survey will in any way jeopardize services to my child or family.

I hereby give permission for the Family, Infant and Preschool Program to use the information obtained in this study for the purpose described above.

_____
Signature

_____
Date

pc

VITA

Carol Marie Trivette was born in Hickory, North Carolina on November 12, 1954. She grew up in Hickory and attended public school until she graduated from Hickory High School in June 1973. Higher education was pursued the following Fall when she attended High Point College. Two years after entering college, she transferred to the University of North Carolina at Chapel Hill. In June 1977, she graduated with a Bachelor of Arts degree in Sociology with departmental honors.

For the next two years, Ms. Trivette was the lead teacher in the TEACCH (Treatment and Education of Autistic and Communication handicapped CHildren) classroom in Whiteville, North Carolina.

In the Spring of 1980, she entered Appalachian State University and began working towards certification and a Master's degree. She graduated in May 1982 and received a Master of Arts degree with a concentration in the Severely and Profoundly Handicapped.